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Multi-culturalism & Alzheimer's Disease: Patient-centered Design as a New Care Model for Multi-cultural Patients with Alzheimer's Disease

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MULTI- CULTURALISM & ALZHEIMER'S DISEASE

Patient-centered Design as a New Care Model for
Multi-cultural Patients with Alzheimer's Disease

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The multi-cultural demographics of those who are diagnosed with Alzheimer’s disease should be closely examined. From a designer’s standpoint, its cultural traits can foster positive behaviors that lead to better quality of life for patients and caregivers. A patient-centered approach in design was explored in order to shape community-based care that empowers (1) individuality in care services, (2) interpersonal connection in caregiver–patient activities, and (3) a communal culture of being valued via humanitarian approaches.

Introduction

Alzheimer’s disease affects seniors with symptoms that endlessly degrade one’s bodily condition of cognitive ability and behavior. Medical studies of the disease have not progressed over the past century, resulting in more chronic patients becoming institutionalized.¹ Today, the increasing number of these patients has raised sociological concerns regarding possible approaches to sustaining community well-being. These demographics within an institutional setting are projected to become rapidly multi-cultural by putting strains on the care facilities’ capacities to meet their particular needs.²

By examining these cultural and social issues, the designer can discover opportunities to formulate its diversity into an asset that benefits individual and community welfare. Among other disciplines, design contributes in the area of general education and practice in which its problem-solving philosophy into interdisciplinary work influence the way people behave and interact with one another. The following framework of research involved non-pharmacological treatments such as designing personal care methodologies for the multi-cultural demographics concerned by Alzheimer’s disease³ (see Fig. 1). The case studies presented here attempt to innovate community-based and healthcare practices through cultural diversity, the significance of which will be further addressed and evaluated.

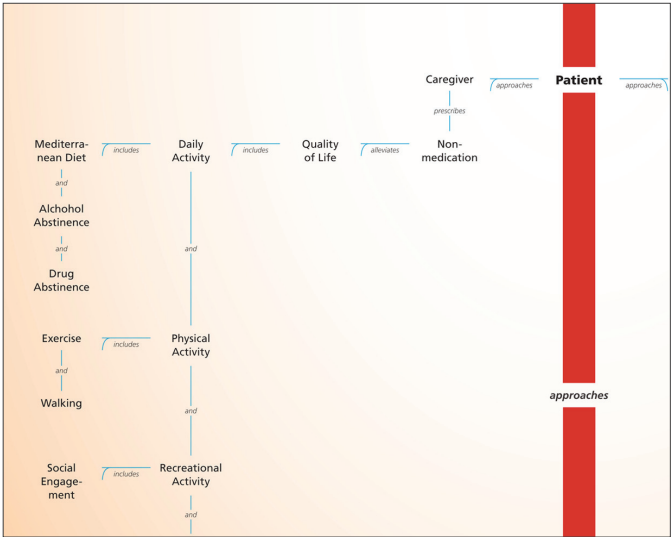
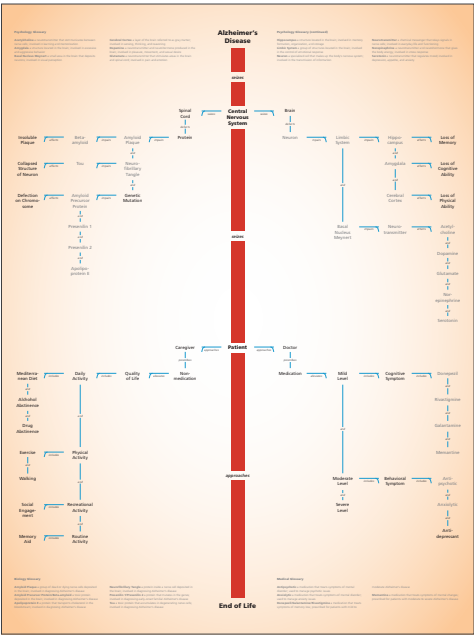


Figure 1. Above, Concept map on the illustration of discipline areas related to Alzheimer's disease. Below, Identified design intervention in non-pharmacological treatments for Alzheimer's disease.

1. Thies and Bleiler, "2013 Alzheimer's Disease Facts and Figures," 19–20; Fowles and Greenberg, *A Profile of Older Americans: 2011*, 5.
2. Maslow, "2010 Alzheimer's Disease Facts and Figures," 49; Naiditc and Weber-Raley, "Caregiving in the U.S. 2009," 22.
3. Petersen, *Mayo Clinic Guide to Alzheimer's Disease*, 112.

Contextual Review

Seniors who are diagnosed with Alzheimer's disease underscore the necessity of memory care services and the care facilities' capacities to treat them. Addressing this issue will require that care facility administrators, caregivers, and patients agree upon a common problem and a solution. However, care facility administrators have been reluctant to staff more caregivers for patients with Alzheimer's disease than the minimum required by government regulations. Caregivers experience difficulty in handling work responsibilities and finding quality time for themselves. Patients, in the end, face the risk of receiving generic care services that overlook their individuality.⁴ Thus, understanding this issue in a sociological context requires understanding a *wicked problem*⁵—a problem that is unlikely to be solved because of other interconnected issues, which is ordinary in any domain involving stakeholders with varying perspectives of their own interests.

In this matter, the designer can help mediate and endorse conformity between stakeholders' different perspectives based on their shared values. The designer should take the patient's side when looking into the healthcare arena, particularly those with Alzheimer's disease because they are victimized from a lasting condition that ought to pay more attention to their dependency on others. The typical healthcare model pursues the patient-centered approaches

Contextual Review

integrated by *Planetree model*, which involves formulating care services around the needs of patients and building more collaborative communal settings through healthcare partnerships.⁶ Architects have leveraged this philosophy to create home-like settings for patients at cutting-edge care facilities, which have had positive therapeutic results. It has provided a soothing atmosphere in what is for the residents a new environment filled with new people.

The following design challenge involves formulating care services that could supplement patients’ varying needs in lieu of upscale healthcare support. Patients who are constrained by limited care facilities’ resources cause more behavioral issues, which caregivers often find difficult to address without prescribing medications that have problematic side effects.⁷ A credible approach would comprehensively tailor community-based care so that therapeutic efforts to encourage positive mental health become the foundation for nurturing a healthy demeanor among patients. Abraham Maslow, a humanistic physiologist, suggests that a healthy society must provide access to basic needs so that anyone is free to experience peak desires.⁸ This vision may be difficult to achieve, given the vulnerable circumstance of patients and caregivers, but a more modest goal is to open up opportunities to move toward these conditions (see Fig. 2).

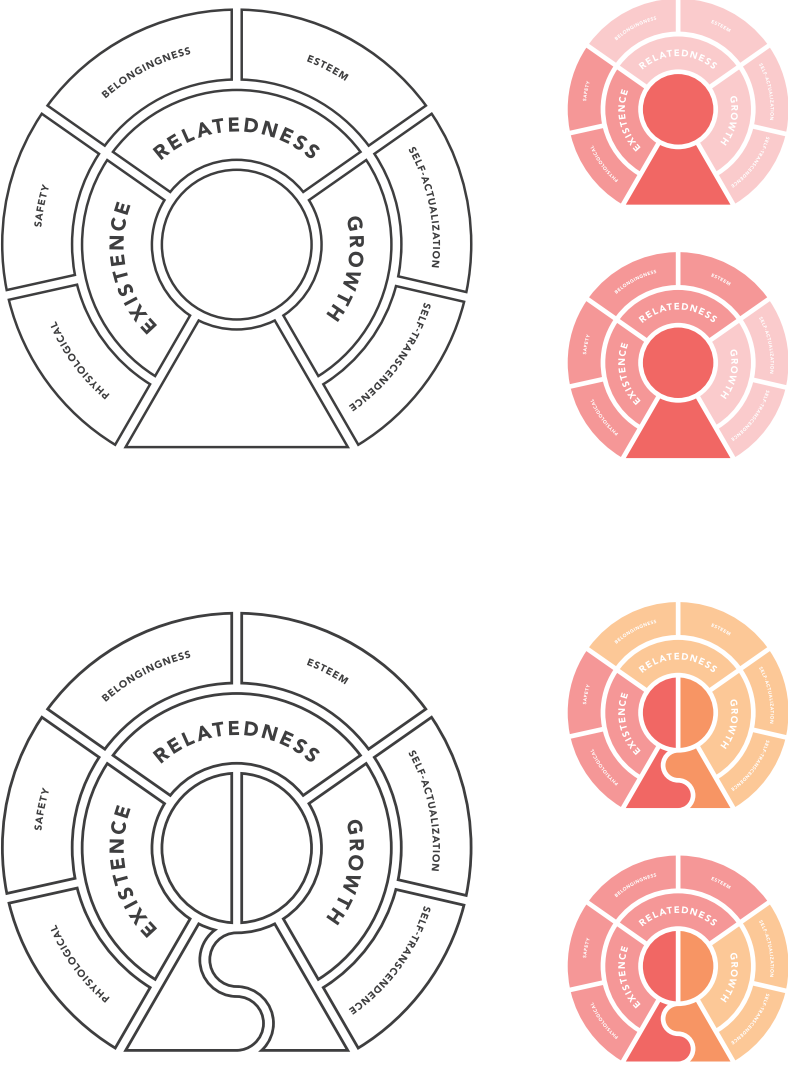


Figure 2. Above, Concept diagram on the constitution of patient's basic needs and desires. Below, Illustration of caregiver-patient activities leading to mutual benefit that satisfies each other's different needs and desires.

4. Feuerberg, *Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes: Report to Congress*, 5; Naiditch and Weber-Raley, "Caregiving in the U.S. 2009," 17–18.

5. Rittel and Webber, "Wicked Problems," 272–280.

6. Brawley, *Design Innovations for Aging and Alzheimer's*, 249–260.

7. Cameron, "Medications: A Double-edged Sword."

8. Maslow, *Motivation and Personality*, 31.

Methodology

Forethought about multi-culturalism can help caregivers handle the issues of diversity as they relate to Alzheimer’s disease. The onset of this research examined an outgrowth population of diagnosing patients who were identified as being more culturally diverse than in the past. Compared to the multi-ethnic community of patients, the majority of caregivers are white Americans. So long as if each care facility employs a minimum of two to three caregivers going forward, they expect higher chances of dealing with ethnical confrontations.⁹ Such analyses set the research agenda that both community-based and healthcare practices urged the inclusion of appropriate care services for the above-mentioned demographics.

At the outset, this research faced the realistic limitations of implementing personalization into the design. Not all care facilities can manage the supply of quality resources or even caregivers’ innate social skills. Therefore, it is important to engage care facility administrators, caregivers, and patients in the design process by pinpointing their varying demands and shared values. Through interviews and survey questionnaires, licensed caregivers were asked about their potential motives in everyday caregiver–patient activities (see Fig. 3). The results showed that they emphasized the importance of access to better food and interaction.

A role-playing exercise was then observed to gain a deeper

Methodology

insight into those motives from the users’ perspective.¹⁰ The designer was immersed in and imagined community-based care from a minority patient’s point of view. In this exercise, more detailed results described the importance of being able to eat traditional meals, share hometown stories, and gain a lifelong appreciation for developing personal abilities. These underlying desires of food, interaction, and self-realization became the framework for objectifying the necessary design directions.

The case studies presented here explore micro and macro solutions and breakthrough interventions oriented toward a *less-stuff* but *more-people* design of resources and services.¹¹ The melting pot of cultures was an inspiration to pursue a viable design path that raised patients’ and caregivers’ interest in each other’s cultural traits and operated by such institutions without conscious effort. *Human-centered design*, a renowned design methodology that puts end users’ needs, desires, and limitations at the forefront of its process, was iterated to assure the characterization of patient-centered features into the design.¹² Aiming for a wider distribution of care services took into consideration healthcare practices in order to build a common understanding of communal culture that prevails for humanitarian purposes.

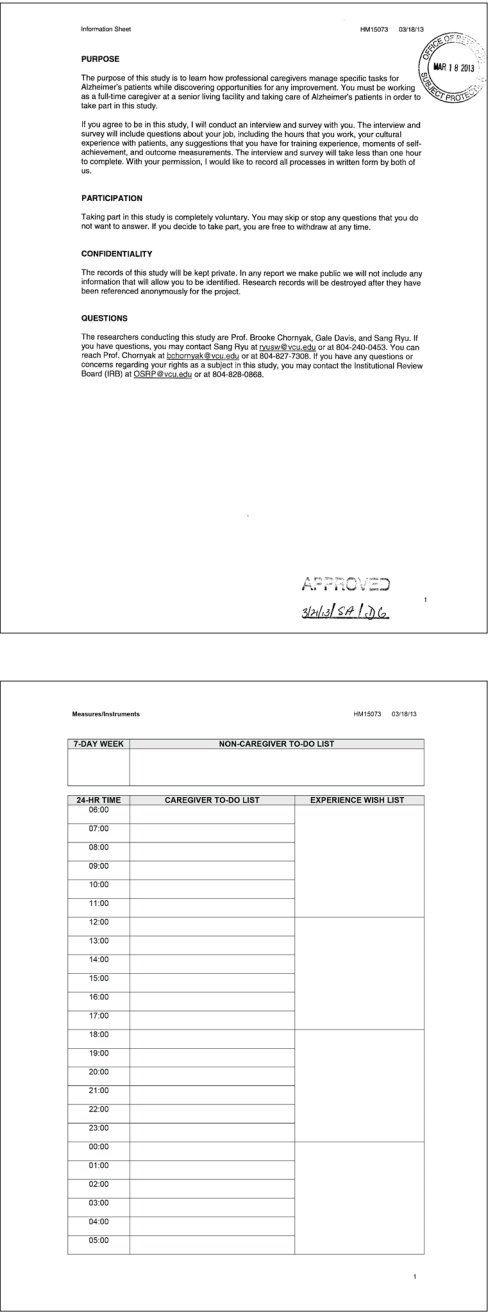


Figure 3. Above, Information sheet on the introduction of the project’s research plan for licensed caregivers. Below, Survey questionnaire to collect experiential responses from licensed caregivers.

9. Naiditch and Weber-Raley, "Caregiving in the U.S. 2009," 22; Polzer, "2013 Assisted Living State Regulatory Review," 231–233.

10. Sanders, *Convivial Design Toolbox*, 66–70.

11. Thackara, *In the Bubble*, 6–7.

12. *Human Centered Design Toolkit*, 8–9.

Case Study: Community-based Practice

Institutionalized patients with Alzheimer’s disease have been deprived of their homes and loved ones thus much more effort goes into soothing their losses associated with the disease. Additionally, institutionalization of multi-ethnic patients increases the levels of loss in terms of the patients’ cultural and historical considerations. In this regard, former case studies exemplified the types of community-based care suitable for minority patients with the purpose of improving their quality of life. Latter case studies took a nonlinear approach and exemplified how these practices could lead to mutual benefits through multi-ethnic caregiver–patient companionship (see Fig. 2).

Information gathered from prior research, including data on the motives of food, interaction, and self-realization, were used as criteria in evaluating different levels of community-based care that encouraged positive behaviors¹³—food to satisfy the needs of *existence*, interaction to satisfy the needs of *relatedness*, and self-realization to satisfy the needs of *growth*. Design ideas and prototypes, through balancing users’ *desirability* and organizations’ *feasibility* and *viability*, have focused on the economics of saving time and having a marketable presence in underserved communities.¹⁴ In the following case studies, paired explorations present one-way and two-way community-based practices that satisfy patients’ *existence* and *relatedness* needs while stimulating caregivers’ *growth* needs.

Food as *Existence* Satisfaction

Overview

Minority patients have unique cultural backgrounds, including a familiarity with their own ethnic and traditional foods. Such foods comfort them by evoking good memories of home.

Insight

Caregivers’ limited knowledge or skill in cooking authentic food restricts the ability to supply this necessity to minority patients. Finding serviceable routes within local channels is suggested.

Work

A vending machine equipped with imported refreshments was placed at the care facility. Allocated items were served to Asian and Hispanic patients at their convenience (see Fig. 4).

Results

Patients benefited from having stationary choices to increase their appetites anytime. Caregivers were able to manage off-duty supplies conveniently. The care facility renewed its in-house presence in a place of interest.



Figure 4. Above, Vending machine installation. Below, Imported refreshment products.

Food as *Existence & Growth* Satisfaction

Overview

Minority patients have unique cultural backgrounds, including a familiarity with their own ethnic and traditional foods. Such foods comfort them by evoking good memories of home.

Insight

Caregivers’ limited knowledge or skill in cooking authentic food restricts the ability to supply this necessity to minority patients. Finding serviceable routes within local channels is suggested.

Work

A catering truck visited the care facility for mealtime appointments. Caregivers guided patients in obtaining Asian and Mexican cuisine depending on their preferences (see Fig. 5).

Results

Patients’ willingness to walk outside allowed a big increase in their appetites. Caregivers were introduced to their authentic foods and were inspired to befriend the patients. The care facility opened a scenic food court in the community.

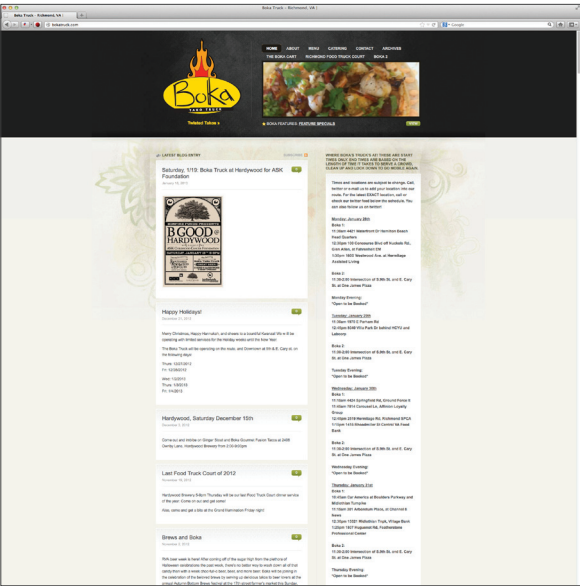


Figure 5. Above, Scheduled locations of Boka catering truck. Below, Catering truck’s visit to the Hermitage Assisted Living.

Interaction as *Relatedness* Satisfaction

Overview

Minority patients have unique historical backgrounds in which their traditions can be preserved. Such commemoration reminds their acquaintances of their origins, which they are proud of.

Insight

Caregivers are unfamiliar with minority patients’ life journeys, making it difficult to find the opportunity to get to know patients. Devising interaction with patients can make the experience appreciated, and is therefore suggested.

Work

An online schedule reminder catalogued patients’ own anniversary dates, such as national, religious, and even seasonal holidays. Near these dates, instant group text messages were sent to caregivers’ mobile phones to remind them of the celebrations (see Fig. 6).

Results

Patients felt restful in the affairs that caregivers cherished. Caregivers built bonding relationships with patients. The care facility espoused its interests to hold festivities more often in the event of meaningful celebrations.

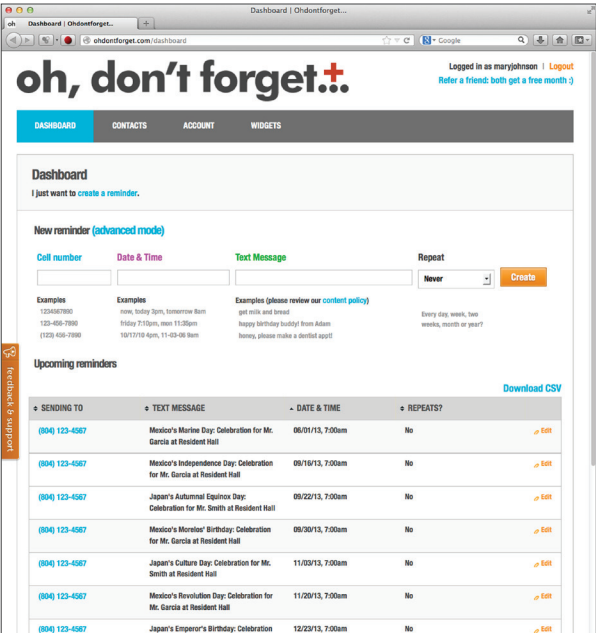


Figure 6. Above, Oh, Don't Forget's schedule reminder website. Below, Scheduled text message alert for mobile phones.

Interaction as *Relatedness* & *Growth* Satisfaction

Overview

Minority patients have unique historical backgrounds in which their traditions can be preserved. Such commemoration reminds their acquaintances of their origins, which they are proud of.

Insight

Caregivers are unfamiliar with minority patients’ life journeys, making it difficult to find the opportunity to get to know patients. Devising interaction with patients can make the experience appreciated, and is therefore suggested.

Work

A signage was hung on the doors of patient wards. During the day, the front showed the floor plan of patients’ locations of valuable goods. At night, the backside displayed patients’ family portraits and photographs as location aids (see Fig. 7).

Results

Patients enthusiastically talked about their valuable goods to caregivers’ inquiries. Caregivers learned personal and life lessons. The care facility renovated each ward into a storytelling venue for residents and visitors.



Figure 7. Above, Signage on each ward's door at the Hermitage Assisted Living. Below, Front signage with the floor plan of a ward and back signage with a collage of family photos.

13. Alderfer, *Existence, Relatedness, and Growth*, 24–29; Maslow, *Motivation and Personality*, 42–45.

14. *Human Centered Design Toolkit*, 6–7.

The lack of preventive treatment in Alzheimer’s disease accelerates the diagnoses of patients, so that the maintenance of a healthy lifestyle from an early age becomes the typical assumption in reducing the coming risks. Making appropriate decisions about active living is becoming the priority for elderly planning and this awareness to the general public should make for a larger population of healthier people. The case studies have incorporated innovative disciplines into healthcare practices, which could persuade intergenerational demographic groups to realize the need for self-care (see Fig. 2). In this regard, innovation requires patient education, reaching out for more than an improved understanding, such as gaining informed skillsets in order to take responsible actions for themselves and their loved ones.

Innovative approaches in reaching the broader demographics through *demographic change*, *new knowledge*, and *perception change* were reflected to influence the disinterested group.¹⁵ Community access to healthcare resources was promoted through unconventional advertising techniques such as *toy*, *social network*, and *transit* advertising so that each technique attempted in-depth communication with a particular age group. In the following case studies, each exploration presents the cultural introduction of free healthcare resources for children, teenagers, and young adults.

Self-realization as *Growth Satisfaction*

Overview

Intergenerational groups can make lifestyle changes to benefit their own well-being. Such awareness of healthcare can be encouraged through learning about prevention, risks, and practices that alter the future health status.

28

Insight

Children, who are not yet independent, are less likely to be in control of their health status. Stimulating their willingness to adopt good health behaviors is suggested.

Work

Let's Move's public campaign was geared toward helping youth avoid childhood obesity. The program publicly distributed promotional plates at schools and at its organized events. Children participated in activities associated with maintaining a healthy weight (see Fig. 8).

Results

Children reacted to the entertaining questioning that appeared on the plates after meals were finished, and enjoyed playing out in the schoolyard. Parents were informed of public programs aimed at supporting creative parenting for healthier childhoods.

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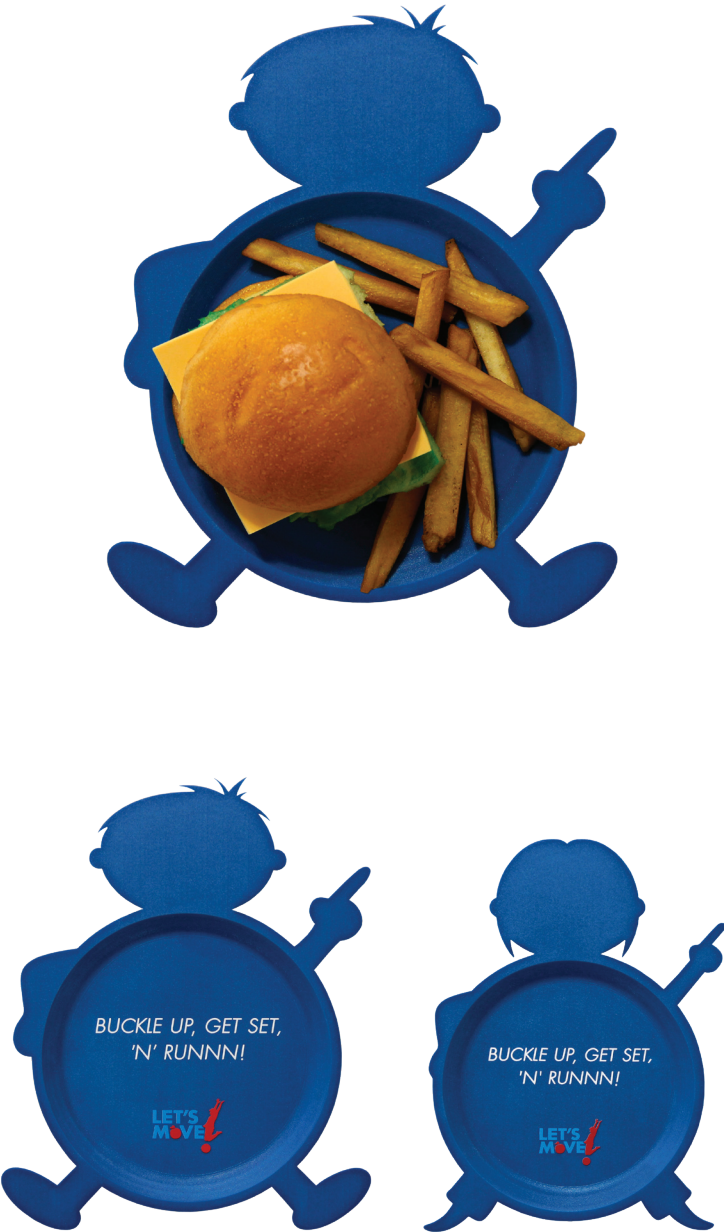


Figure 8. Above, Let's Move's promotional plate before a meal. Below, Promotional plates after a meal. The text says, "Buckle up, get set, 'n' runnn!"

Self-realization as *Growth Satisfaction*

Overview

Intergenerational groups can make lifestyle changes to benefit their own well-being. Such awareness of healthcare can be encouraged through learning about prevention, risks, and practices that alter the future health status.

Insight

Teenagers, who are not yet independent, are less likely to be in control of their health status. Stimulating their willingness to adopt good health behaviors is suggested.

Work

The Alzheimer’s Association contributed studies on emerging facts related to Alzheimer’s disease. An easily downloadable banner file in promoting the most recent statistical diagnosis was shared and posted on various personal websites, including blogs (see Fig. 9).

Results

Visitors viewed the banner on peers’ blogs, where members of the family tree presented faded away due to the increased diagnosis rate over time. This disturbing image passed the words to other people and encouraged them to learn how to prevent themselves from its harm.

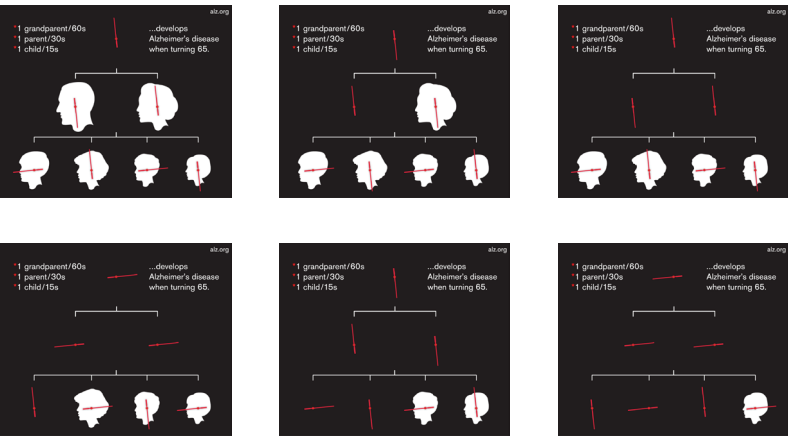
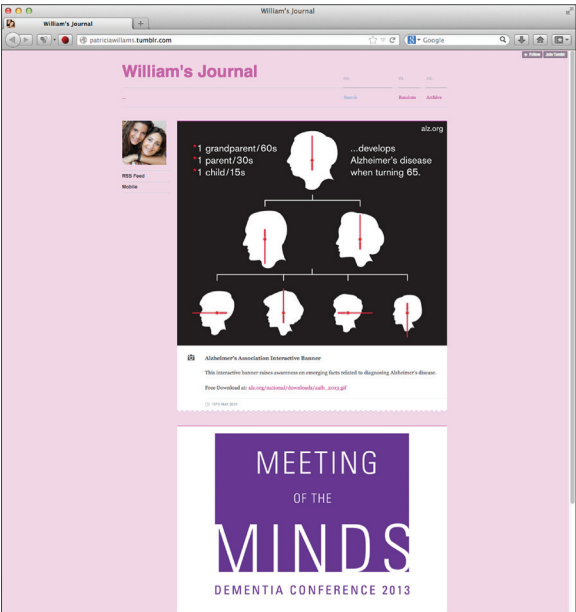


Figure 9. Above, The Alzheimer’s Association’s promotional website banner on Tumblr. Below, Animation of the promotional website banner. The text says, “1 grandparent/60 seconds, 1 parent/30 seconds, 1 child/15 seconds develops Alzheimer’s disease when turning 65.”

Self-realization as *Growth* Satisfaction

Overview

Intergenerational groups can make lifestyle changes to benefit their own well-being. Such awareness of healthcare can be encouraged through learning about prevention, risks, and practices that alter the future health status.

Insight

Young adults, who are not yet independent, are less likely to be in control of their health status. Stimulating their willingness to adopt good health behaviors is suggested.

Work

Mindfulness Day was held as an annual event for meditation practices that support the sole existence of the present moment. Promotional headrest covers were placed on travel bus seats so that the anniversary became widely known among passengers (see Fig. 10).

Results

Travelers were informed of the opportunity to learn about finding peace of mind. Their participation made them more aware of the importance of being happy in the moment and using it to more thoughtfully care for their loved ones.



Figure 10. Above, Mindfulness Day promotional headrest cover. Below, Promotional headrest covers on travel bus seats. The text says, "Find peace of mind on 09/12/13."

15. Drucker, "The Discipline of Innovation," 149–157.

16. Peterson, *Character Strengths and Virtues*, 3.

Conclusion

Research on vulnerable groups such as patients with Alzheimer's disease sometimes finds difficulties in responding to their practical needs or wishes. Design discipline, on one hand, applies a solution-based approach to turn ill-defined problems into generative solutions. The outgrowing number of patients with Alzheimer's disease and the unprecedented number of communities with multi-cultural patients represented an opportunity for the designer. Through social innovation, design has turned these communities into a cultural sanctuary. The designer's initiative in therapeutic means supplied the cultural resources to maintain self-care, quality of life, and healthy lifestyles.

While medical practice offers the ultimate result through groundbreaking treatments, this is often a time-consuming process. For that reason, design practice can formulate alternative, yet immediate, results such as fostering positive behaviors. The World Health Organization defines health as a resource for everyday life, not the objective of living. Designing healthcare for patients with Alzheimer's disease must involve humane values to bring a sickening society back to a healthy life. After all, the designer's challenges discussed can stimulate our inherent characteristics in terms of human strengths and virtues into worthwhile practices that eventually become more influential to the masses.¹⁶

Acknowledgement

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I would also like to thank the volunteers from the Hermitage Assisted Living for sharing their experience and resources during the course of this investigation.

This thesis is dedicated in loving memory to my grandmother, Jae Hee Hong (1913–2011), who suffered from dementia in her later years, and to all of my family.

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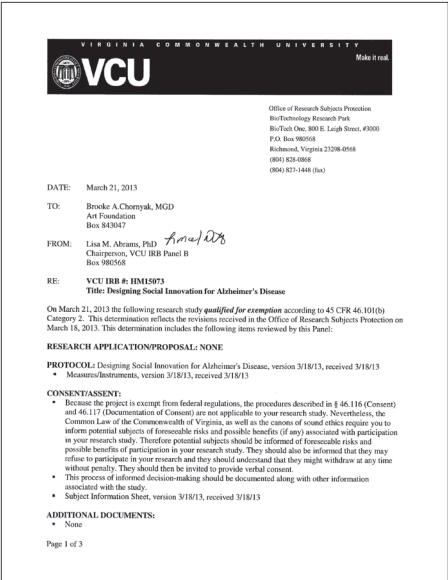


Figure 11. Above, CITI Basic Course Certificate to conduct responsible research activities for the protection of human subjects. Below, VCU Exempt Human Subjects Research protocol to validate interviews and surveying activities.

